

Oncology Nursing Society

Testimony for the Record in Support of H.R. 3119, Palliative Care and Hospice Education and Training Act

Before the House Energy and Commerce Health Subcommittee Hearing Titled “Examining Legislation to Improve Public Health”

Thursday, September 8, 2016

Chairman Pitts, Ranking Member Green, and members of the Subcommittee, the Oncology Nursing Society (ONS) would like to thank the House Energy and Commerce Health Subcommittee for the opportunity to share ONS’ views on H.R. 3119, the “Palliative Care and Hospice Education and Training Act” (PCHETA).

Our written testimony discusses the need to improve palliative care for patients with cancer or other serious or life-threatening illnesses. Oncology nurses have a pivotal role in offering palliative care for people living with a cancer diagnosis. Oncology nurses listen to what is important to patients as they assess how cancer and its treatment impact their physical, emotional, spiritual, and social well-being. Oncology nurses work with other health care providers to assist patients to manage symptoms, obtain community resources for care at home, and support patients in their final days with direct physical care at the end-of-life.

All patients with cancer can benefit from palliative care. Congress can improve access to palliative care by advancing the bipartisan PCHETA legislation introduced in the House by

Representative Eliot Engel and Representative Tom Reed and in the Senate by Senator Tammy Baldwin. ONS greatly appreciates the many members of the Energy and Commerce Committee who have demonstrated their support for this legislation by cosponsoring the bill.

PCHETA seeks to improve palliative care through education, awareness, and research. Not only do we need more trained interdisciplinary palliative care providers, but we need to expose more providers in general to palliative care training. The projected shortages of oncology providers are real and frightening. A shortage of oncologists will not only result in delays in treatment, but also delay conversations about goals of care. Increasingly, oncology nurses and primary care providers will need to be prepared to offer appropriate physical and behavioral symptom assessment and management and guide patients toward achieving their goals of care with effective communication skills and advanced care planning.

ONS applauds the committee for leading the way to realize the Cancer Moonshot and Precision Medicine initiatives through the passage last year of H.R. 6, the 21st Century Cures Act, and we hope Congress will soon complete its action on this legislation. However, health professionals must be ready to meet these needs. PCHETA will ensure we train more nurses, physicians, social workers, pharmacists and others in palliative care. Importantly, the bill follows the successful model of the geriatric education programs and ensures the training of teachers and that individuals are drawn to the field and retained.

Better awareness of palliative care by providers and the public also is necessary. PCHETA builds on existing authority at the Agency for Healthcare Research and Quality (AHRQ) and

provides for the establishment of a national campaign to inform patients, families, and health professionals about the benefits of palliative care and the services that are available to support patients with serious or life-threatening illness. The awareness campaign would include the dissemination of information, resources, and materials about palliative care services in a variety of formats. In planning for the campaign, AHRQ is required to consult with relevant stakeholders.

For most people, cancer will be a chronic illness that will require treatment and support through a journey that begins with a single step – usually a biopsy or an abnormal scan. Understanding that “wanting everything done” for a loved one will also need to include expert symptom management, emotional and spiritual support and assistance with identifying their “goals of care.” To do this, there must be shared decision making in which there is a conversation with their providers about not only “what’s wrong with you” but also “what matters to you”?

Additional research is needed to determine better ways to relieve suffering throughout the cancer care experience and at the end of life. This is especially true for symptoms such as shortness of breath, delirium, and pain control. Research demonstrates that palliative care works and its impact is measureable. It improves quality of life, results in less aggressive care at the end-of-life with fewer inpatient admissions and less ICU care, lowers emotional distress, and may in some cases actually prolong life. PCHETA, using existing authorities and funds, directs the National Institutes of Health (NIH) to expand national research programs to improve the delivery of palliative care to patients with serious illness. Oncology nurses are very active in palliative care research; the National Institute of Nursing Research funds much of the research in this area.

ONS views the promotion and improvement of cancer symptom management and pain control as a national priority for improving the care of persons with serious illness and their families. As both the medical literature and oncology nurses can attest to, far too often patients with serious illness experience unnecessary emergency department visits, hospitalization and re-hospitalizations, and other medical treatments because they lack the necessary integrated palliative care support needed in the setting of a serious illness.

Palliative care is integral to oncology and indicative of the importance of alleviating physical, psychological, social and spiritual pain and suffering. Oncology nurses stand at the front lines of cancer care and urge Congress to recognize the importance of better treatment and quality of life options, particularly for patients with a diagnosis of cancer. A proactive and integrated approach to palliative care, which incorporates a team-based approach that includes multiple health care providers, will help improve patients' quality of life across the care continuum.

The ONS has an important role in educating oncology nurses about palliative care and is actively educating its membership about emerging trends in palliative care.

The ONS is a professional organization of more than 37,000 registered nurses and other health care providers dedicated to excellence in patient care, education, research, and administration in oncology nursing. The ONS members are a diverse group of professionals representing a variety of professional roles, practice settings and subspecialty practice areas. Oncology nurses are leaders in health care committed to continuous learning and leading the transformation of cancer care by advocating for high-quality care for people with cancer.

The ONS is committed to maximizing the contribution that nurses -- the largest group of health care professionals -- have in reducing chronic illness. More importantly, the ONS is committed to maximizing the contribution of oncology nurses in palliative care and looks forward to working with the Subcommittee to advance this important patient-centered legislation.